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ABSTRACT

The physically disabled are at high risk for psychological problems, yet these issues are not adequately addressed in the professional literature. To assess disabled persons' perceptions of the types of problems they experience, and their need for psychological services, 145 severely disabled persons responded to mailed surveys. Subjects completed the Survey of Consumers which elicited information about their perception of the need for mental health services, including the extent and nature of need and the kinds of services needed or preferred (Part I), perceived barriers to the provision of such services (Part II) and satisfaction with services (Part III). Analysis of the results of Parts I and III indicated that 75% of the sample reported a substantial need for mental health services for the physically disabled. Perceived problem areas were fairly evenly distributed in the areas of personal/emotional, organic/biological, cognitive, perceptual, behavioral, social/interpersonal, marital/family, sexual, self-esteem, alcohol/drug use, vocational/career planning, and the use/development of leisure time. Nearly half the sample (45%) indicated that they had experienced psychiatric problems, although whether or not they had had a psychiatric problem was not related to whether they perceived physically disabled people in general as needing mental health services. The most conservative interpretation of the data suggests a significant need for mental health services for the physically disabled. (JAC)

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The Mental Health Needs of
Physically Disabled Persons:
Their Perspective

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ABSTRACT

The physically disabled are at high risk for psychological problems, yet these issues are not adequately addressed in the professional literature. In an attempt to shed light on this issue, the Center for Rehabilitation Research and Training in Mental Health* conducted a large, multi-phase survey of rehabilitation and mental health administrators, rehabilitation and mental health practitioners, consumers and consumer advocates. This article reports on one of these surveys, rehabilitation consumers and their perceptions regarding the existence of mental health problems among physically disabled persons. The survey also explored their perceptions of the need for mental health services and barriers to the provision of such services.

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INTRODUCTION

The physically disabled are at high risk for psychological problems (Lipowski, 1975), and, despite traditional efforts at rehabilitation, many become grossly seclusive, inactive, and housebound (Castelnuovo-Tedesco, 1981). Yet these issues are not adequately addressed in the professional literature, and the actual frequency of problems such as depression and suicide in the disabled is unknown (Servoss, 1984).

Despite a recent trend toward holistic approaches in the practice of medicine, many medical and rehabilitation service providers have not focused sufficient attention on the mental health needs of physically disabled persons. They continue to treat illness and to prolong life often without considering the quality of that life. Undoubtedly, in some cases this lack of consideration results from the service providers' being unaccustomed to considering such intangibles as the quality of life. (Somers, 1982). In other cases, however, the lack of attention to mental health problems may be an ironic consequence of the movement for equal opportunities for the disabled. Proponents of this movement are used to de-emphasizing the differences between the disabled and the able-bodied in order to aid in the assimilation of the disabled into the mainstream of society. (Vash, 1981). Thus, because of their orientation, many proponents may be reluctant to acknowledge the special mental health problems of the disabled so as not to highlight this difference between the disabled and the able-bodied.

The lack of attention by professionals to the mental health problems of the disabled may partially account for the public indifference to these issues, as reflected in the absence of government planning for the provision of psychological care. While there is a viable public policy for the medical care and the vocational rehabilitation of physically disabled persons,

it is notable that there is no equivalent public policy for the mental health care of these individuals (McNett, 1980).

The problem of unmet psychological needs of the physically disabled, as serious as it may be now, is likely to worsen as the disabled population grows. (Somers, 1982). Ironically, the more successful we are in conquering acute disease and postponing death, the more we increase the incidence and prevalence of long-term disability (DeJong and Lifchez, 1983), and the more we increase the attendant psychological problems.

With this realization in mind and spurred on by requests of disabled persons themselves, the authors conducted a large research project to determine how various groups (mental health and rehabilitation professionals, mental health and rehabilitation administrators, disabled persons, and advocates for the disabled) perceive the needs of physically disabled persons for mental health services. This particular report is part of that project and concerns the perceptions of physically disabled persons themselves. The authors felt that the perceptions of disabled persons, as possible consumers of mental health services, would be most relevant.

Literature Review

Numerous studies document the role of disease in concurrent psychiatric disorders (Eastwood & Trevelyan, 1972). Major depression and anxiety have been shown to follow such diverse disorders as cancer (Plumb, 1974), cardiovascular disorders (Dovenmuehle & Verwoerd, 1962) and gastrointestinal disease (Schwab, Brown, & Holzer, 1968). Psychoses have been associated with Addison's disease (McFarland, 1963), open-heart surgery (Thurer, Levine, & Thurer, 1980-1981) and porphyria (Roth, 1968).

The association between physical disability and the occurrence of mental health problems, though rarely reported, is also striking. The rate of psychiatric disorders among disabled children on the Isle of Wight is nearly twice the rate

among able-bodied children (Graham & Rutter, 1968). Psychological test data of physically disabled applicants for SSDI benefits reveal that 35 to 44 percent suffer from moderate to severe psychoneuroses or personality disorders (Shaffer, Nusenbaum, & Little, 1972). The spinal cord injured have been shown to suffer increased mortality due to self-neglect (Ducharme & Freed, 1980; Hopkins, 1971). In one year, 15 percent of the requests for psychiatric consultation in a physical rehabilitation hospital were related to concerns about suicide risk (Missel, 1978). In a large comprehensive needs survey conducted by the Urban Institute, it was found that, for the majority of severely disabled individuals, social contacts are limited to family members, with very few engaging to any extent in outside activities (The Urban Institute, 1975). In the United States, over four million non-institutionalized persons with severe physical disabilities are unemployed (Wright, 1980).

While these studies suggest the presence of psychological problems among persons with physical disability, they are inadequate in their lack of specificity and consistency with regard to the definition of mental health problems, physical disability, instrumentation, and so forth. They offer little information for policy planners who may wish to develop interventions. Moreover, many ignore the perceptions of disabled persons themselves.

The present study evaluates disabled persons' perceptions of the types of problems experienced by the disabled population and the extent of need of this population for psychological services. It also assesses disabled persons' perceptions of their own need for such services.

METHOD

Subjects

Letters detailing the intent of the research were mailed to 990 severely physically disabled former clients of a state rehabilitation commission who

were randomly selected from the first 10,000 suitably closed cases of fiscal year 1982. All prospective subjects had been designated "severely disabled" by the agency in accordance with criteria suggested by the Federal Rehabilitation Act of 1973. Hence, they all had a disability that seriously limited functional capacity, mobility, communication, self-care, self-direction, work tolerance, or work skills. They were expected to require multiple services for an extended period of time in order to achieve rehabilitation. In order to further ensure that the subjects had a significant degree of impairment, an effort was made to target physically disabled persons who were mobility-impaired and who had one of the following disabilities: spinal cord injury, multiple sclerosis, polio, amputation, cerebral palsy, spina bifida, muscular dystrophy, cerebral vascular accident, or other lower extremity impairment. Subjects may or may not have been successfully rehabilitated by the state rehabilitation agency.

Out of the original sample, 203 responded to our letter of intent and agreed to participate. Of those who agreed to participate, 145 usable surveys were returned. An initial mailing and three follow-ups were used to stimulate response. Data were collected from January through March, 1983.

Instrument

The survey instrument, The Survey of Consumers, was designed by the authors in accordance with Dillman's Total Design Method (1978) and Berdie and Anderson (1974). The questions parallel those of alternate versions of the survey, which will be administered to other groups. Development of this instrument included a critical expert review by a diverse group of 14 professionals with varied perspectives and expertise. Review by the group of experts was performed to ensure sufficient content validity, i.e. that the instrument assess the areas relevant to the mental health problems of physically disabled persons.

The questionnaire contains three sections. Part I concerns the respondents' perception of the need for mental health services and asks questions about extent of need, the nature of need (the kinds of problems encountered by disabled

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persons), the kinds of services needed, and the respondents' preferences for settings of services and for type of professionals to render services. Part II concerns barriers to obtaining mental health services. Part III deals with personal data and gathers information about the respondents' experiences and satisfaction with mental health services. All questions regarding levels of need, satisfaction with services, and barriers to service were based on a six-point scale.

For purpose of concision this report is limited to results of portions of Parts I and III and deals specifically with responses to questions regarding the perceptions of need for mental health services in general, personal need in particular, and the demographic characteristics of the respondents.

RESULTS

Results of this survey will be discussed in the following order: (1) the demographics of the client sample, (2) the perception of the need for mental health services, and (3) the relation between various demographic characteristics and the perception of need for mental health services.

1. Demographics

Using the 145 completed surveys, we found that the age of the respondents ranged from 16 to 76 with a mean of 38.70/ and a standard deviation of 12.9. The greatest proportion of clients (55%) was aged 16 to 39, and a full 88 percent of the survey sample was 55 years of age or less. The greatest proportion of respondents was male (61.3%). Information regarding marital status was requested in the survey ("Are you married, divorced, separated, single?"), and the results indicated that 41 percent of the sample was married, 13 percent was divorced, 8 percent was separated, and 36 percent was single. The level of education of the sample ranged from those who had had some high school education to a small number who had completed

their master's degrees. The greatest percentage had high school diplomas (52%), but 25 percent had either an associate's or a bachelor's degree.

Respondents were also asked to report the nature of their physical disability ("What is your primary physical diagnosis?"). Very diversified responses on this item were received (see Table 1). Of the specific choices available, the majority of clients stated that they had an orthopedic disability (17%), and, of the total sample, 79 (55%) stated that they had a disability which impaired their mobility. The length of time that clients reported having this disability ranged from 1 to 62 years, with a mean of 10.6 years.

Insert Table 1 here

The clients were also asked: "Have you ever had a psychiatric problem?" to which 64 (45%) responded yes and 78 (54%) responded no. If clients responded affirmatively to this question, they were asked to indicate whether they currently had a psychiatric problem (32%), whether they had had a psychiatric problem in the past and a physical disability at the same time (64%), or whether they had a psychiatric problem in the past without a concurrent physical disability. It should be noted that the clients' responses need not have been confirmed by a (33.9%)/ mental health professional. The respondents who indicated that they had experienced a psychiatric problem were asked to describe it further: "Which one of the following best describes your psychiatric problem?" The results of this question appear in Table 2 and indicate that the overwhelming percentage of respondents had more than one problem, and approximately 68 percent stated that they were experiencing personal/emotional problems, either alone or in conjunction with another problem(s). Problems stemming from perceptual, cognitive, organic, or behavioral areas were not mentioned at all, and sexual, marital/family and vocational/career problems were mentioned infrequently (1.4% for each of these areas). Respondents indicated that the length of time that they experienced psychiatric problems ranged from 1 month to 74 months, with a mean of 40 months. A large percentage (79.41%) of the individuals who stated they experienced problems also stated that they received mental health services for them.

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Insert Table 2 here

2. Perception of the Need for Mental Health Services

The major thrust of this survey was to assess the general need for mental health services from the perspective of the physically disabled. The question used was the following: "From your perspective, how would you rate the need for mental health services for severely physically/psychiatrically disabled individuals?" Note that in this section the clients were requested to rate the general level of need, not his or her personal need. The respondent was asked to rate that need on a scale ranging from "no need" to "very substantial need." As can be seen from Table 3, the greatest

frequency of answers (45%) was to the "very substantial need" category. A full 75 percent of the respondents indicated that there is a substantial or very substantial general need for mental health services among this population.

Insert Table 3 here

Further, when clients were asked to rate the general need for services in dealing with various types of problems, they perceived the greatest needs in the vocational, personal/emotional, social/interpersonal, and marital/family areas. (See Table 4.)

Insert Table 4 here

3. Relationship between Client Characteristics and Perception of Need for Mental Health Services

In order to determine if there were any significant relationships between various client characteristics and the perception of general need for mental health services, chi squares were calculated. To prevent sparse tables, the responses to "Perception of Need" were collapsed into three categories: (1) no need or minimal need, (2) moderate need, and (3) substantial or very substantial need.

Age of the respondents was also collapsed into the following three categories:

(1) 16 to 39 years, (2) 40 to 55 years, and (3) 56+ years.

There was no relationship between perception of general need and age ($x^2 = 7.52$, $p < .11$), marital status ($x^2 = 5.29$, $p < .50$), gender ($x^2 = 3.21$, $p < .20$), level of education ($x^2 = 5.23$, $p < .73$), or length of disability ($x^2 = 2.56$, $p < .63$).

The respondents were asked to indicate whether they had a psychiatric problem ("Have you ever had a psychiatric problem?"), and we found no relationship between their answer to that question and their perception of need for mental health services in general ($x^2 = 2.47$, $p < .29$). Of those who indicated that they had experienced a psychiatric problem, perception of general need for mental health services was not associated with whether the individual had experienced their personal psychiatric problem in the past or whether their psychiatric problem occurred concurrently with their physical problem ($x^2 = 3.63$, $p < .46$). Those individuals who stated that they had a mental health problem were asked to indicate whether they had received mental health services, to which 52 (82.54%) responded affirmatively. There was no significant relationship between individuals' perceptions of general need for mental health services and whether they in fact received mental health services for their psychiatric problem ($x^2 = 2.99$, $p < .22$).

DISCUSSION

Physically disabled persons clearly perceive other physically disabled persons as needing mental health services. A full 75 percent of our sample reported a substantial need, and only 8 percent felt that there is minimal or no need. Perceived problem areas were fairly evenly distributed over choices: personal/emotional, organic/biological, cognitive, perceptual, behavioral, social/interpersonal, marital/family problems, sexual problems, self-esteem, alcohol/drug use, vocational/career planning, and the use/development of leisure time.

Naturally, these perceptions should not be automatically attributed to

physically disabled persons in general, for only 21 percent of possible subjects agreed to participate in the study and, of that group, 71.4 percent returned usable instruments. But even in the most conservative analysis, assuming that no single additional person among the non-respondents perceived a need, there would still be approximately 11 percent of randomly chosen physically disabled persons who do perceive a need. This, in itself, is meaningful. The actual percentage who perceive a need is undoubtedly larger.

Just why many prospective subjects failed to respond to the request to participate in this survey is speculative. Some anecdotal evidence suggests that a number of prospective subjects may have misunderstood the intent of the survey and felt that the very existence of such a project implied that they themselves had mental problems. Hence, they may not have participated out of confusion or anger. A few persons reported frustration over their experience with the state rehabilitation agency and refused to complete a questionnaire because of that agency's involvement. A number of letters were returned because of changes in address. Undoubtedly, some persons were too disabled to respond. It should be noted that 71.4 percent of individuals who agreed to participate eventually did submit responses.

The spectrum of respondents to this survey was wide, with diversified characteristics, although the average respondent had been disabled a long time (mean of 10 years), was fairly well-educated (52 percent had high school diplomas), and was at the height of his or her productive years (mean of 38 years old). Though not all respondents were mobility impaired, perusal of the data revealed that all subjects were significantly physically disabled. In fact, at least one respondent was on a respirator.

Interestingly, a full 45 percent of this group reported that they themselves had experienced psychiatric problems, mostly contemporaneous with their physical

problem. This statistic may not accurately represent the incidence of adjustment problems among physically disabled persons, or even among this sample, as it was based on self report rather than on objective observation. Then, too, the sample of persons who chose to respond to the questionnaire may be more likely to acknowledge such problems than the population of physically disabled individuals at large. But even though this statistic may not be technically accurate, it has great value for the planning of mental health services. Whatever the true incidence of mental problems among the physically disabled, it is those persons who perceive a problem who would most likely make good use of services. In the most conservative interpretation of our data, assuming not one person among the original sample of 990, other than the 45% of the 145 who returned usable questionnaires, perceives himself or herself to have a psychiatric problem, then at the very least, 6.5 percent of randomly selected physically disabled persons acknowledge that they have had a psychiatric problem. The actual percentage of physically disabled persons who have psychiatric problems may, in fact, be higher.

The perception of the nature of problems personally experienced by the respondents does not mirror exactly their perception of problems experienced by physically disabled persons in general. Of persons reporting psychiatric problems, approximately 68 percent of the respondents reported personally experiencing personal/emotional problems either alone or in conjunction with another problem. Only 1.4 percent stated that they experienced vocational/career problems. Yet, respondents perceived the greatest need for services for disabled persons in general to be in the vocational area. The need for services in the area of personal/emotional problems was ranked third. The differences in perceptions on need (personal vs. general) may reflect a difference in the format of the question. In the first instance, respondents were asked for the best description of their personal mental health problem. Respondents tended to pick

one or two response entries out of the problem list, many choosing only the first entry (personal/emotional problems). In the latter instance, respondents were asked to rate the level of need for services by disabled persons for each of the response entries. Unlike the first instance, there was no suggestion that the respondent need choose the most descriptive problem, but rather that he/she evaluate the importance of that problem independently of other problem areas. Though the vocational area came out the highest, the actual range of responses was not wide. So, while 54 percent of respondents reported a great need in general, for vocational/career planning services, 36 percent of respondents reported a great need, in general, for personal/emotional services.

There were no significant relationships between perception of need and various characteristics of the respondents: age, gender, duration of disability, marital status, or education. Contrary to expectations, whether or not respondents experienced a psychiatric problem bore no relation to whether or not they perceived physically disabled persons in general as needing mental health services. Respondents were more likely to attribute mental health problems to other disabled persons than to themselves. This may have to do with a tendency to project one's own unacceptable feelings to others, rather than to oneself.

Even the most conservative interpretation of our data suggests a significant need for mental health services among physically disabled persons. Many disabled persons themselves perceive a substantial need. While physically disabled persons are hardly disinterested in this matter, they are the potential consumers of such services. We should take their perceptions seriously.

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Table 1

Primary Physical Diagnosis Reported by Respondents

	<u>N</u>
Spinal Cord Injury	24
Multiple Sclerosis	8
Polio	2
Amputation	6
Cerebral Palsy	8
Spina Bifida	1
Muscular Dystrophy	2
Cerebral Vascular Accident (Stroke)	9
Brain Injury	7
Other Orthopedic Disability	30
Cardiovascular Disease	6
Cancer	2
Arthritis	8
Other	17**
More than 1	10**

N = 140*

* 5 respondents did not answer this question.

** These categories may contain some inaccuracies due to the way the respondents answered the question.

Table 2

Descriptions of Personal Psychiatric Problems Reported by Respondents

	<u>N</u>
Personal/Emotional (feeling overly upset, sad, worried, angry, grief stricken, etc.)	23
Organic/Biological (behavioral and emotional problems resulting from brain disorders)	0
Cognitive (poor memory, inability to think clearly)	0
Perceptual (hallucinations, etc.)	0
Behavioral (too impulsive, too withdrawn, too aggressive, etc.)	0
Social/Interpersonal (overly dependent, lack social skills, cannot cope with others' reactions to disability, etc.)	2
Marital/Family Problems (including family coping with impact of physical disability)	1
Sexual Problems	1
Self (self-concept, self-esteem, self-confidence, self-centeredness, etc.)	4
Alcohol/Drug Problems	3
Vocational/Career Planning Problems	1
Use/Development of Leisure Time	5
Personal/Emotional in conjunction with other problems	25
More Than One of the Above (2 or more of the above problems, except Personal/Emotional)	6

N = 71

Table 3

Perception of the General Need for Mental Health Services

	<u>N</u>	<u>PERCENT</u>
No Need	4	3.27
Minimal Need	6	4.92
Moderate Need	20	16.39
Substantial Need	37	30.32
Very Substantial Need	55	45.08
Dno't Know	0	0

N=122*

* 23 respondents did not answer this question.

Table 4

Perception of General Need for Mental Health Services by Problem Area

	No Need	Min- imal Need	Mod- erate Need	Sub- stan- tial Need	Great Need	Don't Know
Personal/Emotional (feeling overly upset, sad, worried, angry, grief-stricken, etc.) (N=140)	3.57%	5.71%	23.57%	31.42%	35.71%	0%
Organic/Biological (behavioral and emotional problems resulting from brain disorders) (N=108)	14.8	9.25	17.6	15.74	42.59	0
Cognitive (poor memory, inability to think clearly) (N=126)	15.87	9.52	22.22	24.60	27.78	0
Perceptual (hallucinations) (N=107)	27.1	14.02	14.95	21.50	22.43	0
Behavioral (too impulsive, too withdrawn, too aggressive, etc.) (N=129)	10.07	8.52	20.15	29.46	31.78	0
Social/Interpersonal (overly dependent, lack social skills, cannot cope with others' reactions to disability, etc.) (N=139)	10.07	22.23	15.10	23.74	38.85	0
Marital/Family Problems (including family coping with impact of physical disability) (N=132)	11.36	4.55	17.42	28.03	38.64	0
Sexual Problems (N=127)	16.53	7.87	25.98	22.04	27.56	0
Self (self-concept, self-esteem, self-confidence, self-centeredness, etc.) (N=136)	10.29	6.6	20.58	24.27	38.23	0
Alcohol/Drug Problems (N=127)	23.62	8.66	13.39	18.90	35.43	0
Vocational/Career Planning Problems (N=139)	4.32	4.32	15.11	22.3	53.96	0
Use/Development of Leisure Time (N=135)	16.3	10.37	25.93	11.85	35.56	0
Other (N=40)	0.00	2.50	5.00	17.50	75.00	0